

I am alive today

History of an AIDS drug

A film by Vincent Detours and Dominique Henry

Transcript of dialogs
annotated for translators

Notes for translators:

- 1.This document is the reference text for translations.
- 2.Action takes place in the United States and involves characters, institutions, and cultural references from this country.
- 3.Footnotes give indications about technical terms, intentions, etc.
- 4.Text in *italic* describe images and does not need to be translated.
- 5.Upper case words within dialogs are emphasis voiced by the speakers.
- 6.Unless specified otherwise, all dialogs are spoken on screen by interviewees seating against a black background.

* * *

A man is speaking through a microphone. Sound and image quality are poor. My current viral load has been undetectable for 14 months, and my CD4 count has risen above 400 for the first time in a decade. I have not been this healthy in 10 years. What does this mean? This means that I am alive today, likely 20 years after HIV infection because I have had access to the latest medical treatments just as soon as they have become available. I've often been a willing ginea pig in clinical trails to improve each successive generation of therapy.

Black screen reads:

I am alive today

History of an AIDS drug

A man in the street holds a poster reading: GOD sent AIDS TO PUNISH GAYS¹.

Camera zooms out from the face of a young man to a larger scene in a street of New York including the young man, another young man, and orthodox Jewish men.

First young man to the Jewish man who was holding the poster earlier. You've never been... You've never been harassed in the street? No one has never say anything to you?

Jewish man. What do you say? Our request is about gay rights.

A voice off screen. Nothing new.

First young man. I mean, I've seen people harassed. I've seen it happen in the street hundreds times. What happens if they go a step forward and say "you can't live in Brooklyn anymore"? They don't want to rent you because you are making the neighborhood look bad.

Jewish man. We are living in our own community. Nobody rents to us. We're living in our own community.

Man wearing black leather gloves and a black coat argues with the young men in the street. This is an issue of degeneracy! That is an issue that is a health crisis! This is an issue that can spread AIDS!

Second young man. May be I do have AIDS!

Man in black, angry. You are a health hazard in New York City!!! You are a health hazard in New York City! You got a cold, you go to a doctor! You got AIDS, you're quarantined!

Impatient and outraged face of first young man.

Title reads: Mark Harrington, Act Up. It was a big taboo to really talk about it. I think people were so frightened

¹This poster is needed for the understanding of the sequence. "Gay" is a casual but respectful term for "homosexual".

they didn't really know what to say. We would even go to benefits, like a benefit party for "Art against AIDS" or for amFAR² or something, but we wouldn't really talk about HIV. Then there would be friends who would suddenly come down with mysterious things and sometimes they would disappear.

Title reads: Eric Sawyer, Act Up. (The same man as in the pre-title shot.) My boy friend ended up from almost 200 lbs., very athletic, a tennis player. He played on the Stanford team and he ended up so thin from wasting syndrome³ that I could carry him in my arms. In giving him a massage, rubbed him the whole length of his arms with my thumbs touching my finger except for the elbow joint. It was a pretty horrible thing to witness, your lover melting away in front of you, to have to get up in the middle of the night several times to change the bed because he had uncontrollable diarrhea and vomiting. It was a tough time.

Priest yelling through a microphone. Sound is highly distorted. You want to see the end result of this life style?! Then come with me to the hospital and see these young men dying of AIDS!!! Come and see their flesh rotting off their very bones!!

An enthusiastic voice off screen. Right on!⁴

Priest. Come and see their bodies covered with these ugly purple warts, as they loose pounds after pounds!

Eric Sawyer. At that time there actually were beginning to be reports, primarily only in the gay press about cases of what they were calling the "gay cancer". (and) That was followed six months or so later with reports of strange forms of pneumonia in gay men. (and) At that time ironically I developed real severe flu-like symptoms, swollen lymph nodes. They thought I had mononucleosis, they took blood tests then they did a biopsy and cut out some of my lymph nodes from under my armpit and tested for Hodgkin's disease, a form of lymphatic cancer. (and) None of that was present, so they weren't quite sure what was

²amFAR: American Foundation For AIDS Research. This is the first AIDS charity set up in the US.

Reference to amFAR can be omitted.

³Wasting syndrome is an AIDS-related condition causing dramatic weight loss and fatigue.

⁴Can omit.

going on with me, but my health was a bit strange.

Title reads: David Barry, vice president for research, Burroughs Wellcome. We were one of the few companies that were very, very active in antiviral therapy at the time. Because we believed that antivirals were a real possibility. Many people at the time felt barry04 that you really couldn't produce an antiviral drug because the virus lives inside the cell, perverts the function of the cell to its own purposes and therefore in order to kill the virus you had to kill the cell.

Title reads: Hiroaki Mitsuya, researcher, National Cancer Institute. In May or April or May in 1984, Bob Gallo gave me, gave us, HIV-1⁵ preparation. And then what we could do was, when we discussed with Dr. Broder, to develop, potentially, antiviral agent which could suppress the replication of the virus, the new virus HIV-1.

David Barry. And it so happened that we had a drug, called BW509U at the time, that had been invented in 1964 --- first synthesized⁶ in 1964 --- in Michigan by Dr. Horwitz, but as a potential anticancer agent but was subsequently abandoned. [cut] We gave the compound to our laboratory people who did some tests against two different retroviruses of mice.

Hiroaki Mitsuya. At that time I, I had injected myself with tetanus toxoid more than seven times, and then I was a very great responder, high responder to tetanus shot. And then I thought myself would be a good candidate because I wanted to generate many T cell clones. Normally functioning T clones. And then my plan was to infect those normal T cells. [cut] Of course then I was seeing the killing of my CD4 positive T cells by HIV-1 after exposure to the virus. I was seeing dead cells. But I had to rescue those dying cells with some potential drugs which I didn't have.

David Barry. Because again we didn't have access to the human retrovirus, we sent out the compound, but under a coded name, simply called "Compound S" to three laboratories that did have access to the human virus.

⁵Can omit "1" in "HIV-1".

⁶The fact that Barry correct himself by saying "synthetized" after "invented" is important and should be translated.

Hiroaki Mitsuya. Burroughs Wellcome sent AZT and AZT was effective in my own evaluation system. And several other institutes concluded AZT was not working, but it worked beautifully in my system because I was using human retrovirus and human cells, target cells, that was the best combination.

Eric Sawyer. My boy friend actually died on an airplane on his way to visit his mother with his secretary, who was a 25 year old woman, because my company would not give me the day off from work to travel with him to visit his parents. I was so angry that he died alone without me and that... [nearly crying] I wasn't there to say good-bye to him, that I vowed I would never allow myself to have my voice, my activities or my movements limited and that I would fight for human rights and human dignity.

Angry man speaks through a microphone. Title reads: Larry Kramer, founder of Act Up. I am not going to commence these remarks with the recital of all the latest figures and case numbers and infections per second and deaths per milimoment⁷. That's how I always use to begin. That's how everybody usually begin. Facts! Figures! How many infected! Dying! Dead! No more! [cut] Why do I keep getting invited to make more of these speeches?! Why do you listen to me?! I have no more brilliant idea! I only had one anyway, one lousy idea: FIGHT BACK⁸!

David Barry. Now at that time, the controversy about the availability, the affordability, the accessibility of AIDS drugs began. But the tenure and pitch of it at that time was not extreme. The original price of AZT was relatively high --- about \$10,000 per year --- but we knew that there would likely be other drugs that would come along to displace it and therefore we had to recoup our investment in a very short period of time.

Title reads: Wall Street, 1987. Crowd and two men with loud speakers yelling slogan. Burroughs Wellcome just like thugs!
Triple profits with their drugs!

⁷Milimoment: some imaginary tiny time unit.

⁸Do not use infinitive forms here. Kramer means: you, the audience, fight back.

Burroughs Wellcome just like thugs!
Triple profits with their drugs!...

Cameraman runs with demonstrators. Camera points toward the ground. Voices off screen. Join them! Join there!

*Demonstrator sitting and yelling. Release the drugs!
Release the drugs!*

Police arrest demonstrators, carrying away them on stretchers.

What do we want?!

A cure!

When do we want it?!

Now!

What do we want?!

A cure!

When do we want it?!

Now!...

Demonstrators pointing fingers at people off-screen. You can get it too! You can get it too!...

Title reads: Eric Sawyer, Act Up. We were outraged that the drug was being priced higher than any drug had ever been priced before and it was only because it was gay men that primarily needed it and because you died if you didn't have something to help you stay healthy from AIDS. (and) People were dying at that time within one to two years of being diagnosed. It was profiteering on the fear and desperation of very ill and dying patients that was allowing them to charge that ridiculous price. (so) We were more than happy to organize our first demonstration at Wall Street to target the financial community for its investment in the -- - at that time --- Burroughs Wellcome Company, which was pricing that drug so outrageously.

Title reads: Peter Arno, economist, Montefiore Medical Center. Well when AZT was first marketed at \$10,000 a year, congressional hearings were immediately called and they blasted the then president of Burroughs Wellcome, this guy by the name of Haigler. They questioned him over and over again in trying to justify the price of the drug. And I can recall that then Congressman Wyden --- now Senator Wyden -- - he kept asking Haigler, "Well, why did you make it

\$10,000 a year? Why didn't you make it \$100,000 a year?" and all that the president of Burroughs Wellcome could say was that it was a reasonable price, that they had to recoup their research and development costs, which as we know were rather minimal in this case because a lot of the work had been done prior to Burroughs Wellcome getting involved.

Title reads: David Barry, vice president for research, Burroughs Wellcome. Drug companies can make profits in many diseases and many conditions even that aren't disease, like baldness. And to get them involved in a disease, you have to show they can make money. And we were making money and some of the other drug companies were starting to get interested.

Title reads: Mark Harrington, Act Up. So they already make⁹ \$600-700 million --- this was in the first 18 months. It's a very profitable drug. They're already making... they're making a lot of money off it.

David Barry. There had been so much animosity towards us from the activists that we felt it was best to figure out A) what the concerns were and B) to explain the many factors.

Mark Harrington. And we met with David Barry and it's a big tobacco state so you could still smoke inside in those days. (and) He was a chain smoking virologist from Yale who was very slick and smooth and smart.

David Barry. The discussions themselves were not very fruitful. We told them all the reasons why the price had to be what it was. They told us the reasons why they didn't like that.

Mark Harrington. A drug is this mystical combination. You've got pay for all the drugs that didn't work out --- and they always exaggerate the number and they exaggerate the amount that they spent on them.

David Barry. What we didn't know is they had drawn maps of where things were while we were taking them through the corridors and a couple of weeks later they broke into our

⁹Harrington tends to use present form for past actions. This can be corrected in translations.

laboratories.

Mark Harrington. They barricaded themselves in the room and they hung a banner over the window and called all the media and... [*turning his head down*] and got arrested.

David Barry. So we had... we called in the local sheriff's office and had them arrested.

Peter Arno. Any drug that comes to market in the United States must be approved by the Food and Drug Administration¹⁰ before it's approved¹¹ and they are supposed to test and assure the new drug product is... been tested for safety and effectiveness before it's marketed.

Eric Sawyer. The whole process would take anywhere from ten to fifteen years to have a drug approved for marketing and people with AIDS were dying in one to two years of diagnosis, so we were saying, "Look, we're going to be dead in a year or two anyhow! Let us be guinea pigs! Let us take poison if we want to risk that! We know we're going to die without effective treatments. We're willing to risk our lives to come up with effective treatments. Shorten the drug approval process! Use us!"

Title reads: Montreal, 1989. Crowd in a conference room. Act Up posters. A voice off screen. Les organisateur de cette cinquième conférence sur le sida tiennent particulièrement à remercier le gouvernement du Canada pour son appuis inestimable.¹² Ladies and gentlemen the Prime Minister of Canada, the very honorable Brian Mulroney.

Prime Minister of Canada walks to the podium of the conference hall --- smiling and shaking hands of officials on his way. Applauds mixed with voices boohooing.

*Brian Mulroney on podium.*¹³ Together with all the people of the world, Canadians hope that this conference in Montreal will be a milestone in that journey...

A skeptical female voice off screen. Yeah, right.

¹⁰Food and Drug Administration: Drug regulation authority in the US.

¹¹Approved: he means "marketed"!

¹²The organizers of this fifth AIDS Conference thanks the government of Canada for its valuable support.

¹³Translation should reproduce the emptiness of Mulroney's rethorics.

Brian Mulroney. This week, scientists will exchange data from thousands of research projects, aid an understanding of this epidemic, and bring the day of a vaccine and a cure closer.

Female voice off screen, tired. I'm so sick of this vaccine song.

Panning shot on the public. Camera pans from a banner reading "MULRONEY you let us die" to Mulroney at the podium. A hand in the foreground holds a watch. Watches are beeping all over the place while Brian Mulroney keeps talking in the background. A great many people in Canada and around the globe have been working many months to make this conference a success. On behalf of the government and the people of Canada I want to thank all of you...

An exasperated male voice off screen. Oh, cut the crap!!!

Brian Mulroney. I appeal to the Canadians and to people everywhere. This fight knows no frontier...

Female voice off screen. Thanks for the pep talk Brian.

Brian Mulroney. This fight is everyone's responsibility. Let us beat ignorance with education and information. Let us beat suffering with compassion and tolerance. Let us all unite and beat and defeat this appalling adversary.

Brian Mulroney leaves the podium. Panning shot on the public. Off-screen voices over applauds. Hypocrite! Booh!!! Booooh!!! Booooooh!!!

Mark Harrington. Montreal was really a major breakthrough for us because it was the fifth international AIDS conference, but this time the treatment and data comity decided to write a strategic plan or research agenda and give it to the government because we figured that they didn't have one and they needed one [*he laughs*]. So we wrote it ourselves, and brought it to Montreal.

Mark Harrington speaks on a podium. Title reads: Montreal,

1989. Bonjour Messieurs et Mesdames de la presse.¹⁴ Good afternoon. I'm Mark Harrington from Act Up. Today we are introducing an agenda for AIDS treatment and research, and for regulatory reform in the United States. Although this is restricted to the United States, we believe that the United States has global responsibility to quickly develop effective treatments, not only for HIV infection itself, but for all the opportunistic infections which actually cause death of people living with AIDS.

A man at same podium speaks with forceful, angry voice. The AIDS program of the United States run by the National Institute of Health¹⁵ under the National Institute of Allergies and Infectious Diseases¹⁶ has failed by any measures. They have already spent \$400 million this year, and yet as Mark said earlier, they have given us no therapeutic agents -no effective therapeutic agents- against either HIV or the opportunistic infections. They have given us no preventive drugs. But not only that: they haven't given us any useful information. This has to change!

Another man, same set up. This is it! [*Showing yellow pamphlet.*] This is the plan we're presenting! We need our government to read this plan, we need them to work with us. If they want to change it a little, we'll talk to them. But I want them to adopt it. I want them to get started on it, I want them to save our lives. Thank you.

Mark Harrington. That resulted in new relationships with the policy makers at the Food and Drug Administration and at the National Institute of Health so that we started working with them to work on designing expanded access programs¹⁷. But the scientists were still very resistant to participation of activists in the actual research, the protocols themselves or the clinical trials. [*cut*] We had to do another giant national demonstration at the National Institute of Health in Bethesda, Maryland in May of 1990 to force the government researchers and the government-sponsored researchers in the universities to let us be part

¹⁴Ladies and Gentlemen from the media, good afternoon. Can omit.

¹⁵Institution supervising biomedical research in the US.

¹⁶Can be reduced to "National Institute of Immunology".

¹⁷Expanded access programs: clinical trails designed such that the drugs being tested are available to more patients.

of that system, that actually designs and conducts the clinical trials, the publicly funded clinical trials. And so by the summer of '90, we had a new structure where activists and people with HIV were represented on all the research committees of the National Institute of Health.

David Barry. We, at the same time, were conducting a number of other studies and the National Institute of Health was conducting a number of other studies for which we were supplying drug --- for free. And one of those studies showed, in 1988-89, that the drug was useful in patients who had less advanced HIV infection and in fact was beneficial if you were just positive for the virus. This greatly expanded the number of patients who were likely to receive the drug and also, during the period from 1987 to 1989, the number of patients with the disease also increased very markedly. That was on the very steep up slope of the epidemic.

Eric Sawyer. They were able to put out a preliminary report showing some success in life expectancy by taking this drug and it encouraged a lot of people to rush to their doctors and demand to be on it. I myself went on the drug at that time too, because I thought it might prolong my life.

Peter Arno. The results of the 019 trial¹⁸ were announced by the Secretary of the Department of Health and Human Services¹⁹ on August 17th, 1989. (and) Because the market for the drug had grown so dramatically, the stock market also took it in stride and within one day, the very next day, the stock for Burroughs Wellcome had shot up 32% on that day.

Title reads: Wall Street, 1989. People waiting to enter some building. A voice off screen. Hey! I gotta get to work!

A woman. I got a minute to clock in! He says the buildings are closed.

Demonstrators off screen. We die! They make money!...²⁰

¹⁸019 trial: the study Barry was referring to.

¹⁹Secretary of the Department of Health and Human Services: US minister of health.

²⁰This slogan is repeated forcefully at the end of the sequence and may be omitted here in order to concentrate on people trying to get to work.

Policemen and cameraman run after three demonstrators. Policemen push them on the ground. Other demonstrators off screen. No violence! No violence!...

People lying on the ground are being handcuffed by policemen. Voices off screen.

Act Up!

Fight back!

Fight AIDS!

Act Up!

Fight back!

Fight AIDS!...

An angry man in trench coat and sun glasses talks to camera. Part starts off screen. Look the bastards! They... they are not defacing a building?! They are not making public unrest?! Oh, that's not militant shit!

Policemen carry a young woman to a police car. She opposes no resistance, but keeps shouting. We die, they make money! We die, they make money!...

A policeman takes a Polaroid picture of her while she is brought into the police car.

Mark Harrington. And they walked in right before the bell sounds and they opened for business. They were blowing horns and they were dropping their banner that says "Sell Wellcome". So they got inside the Stock Exchange and again made a lot of news.

Eric Sawyer. The fact that we could infiltrate the halls of power, the Wall Street Stock Exchange really irritated all of those companies, really irritated our government and also forced them into doing something to find a cure and into lowering prices and there was a price reduction after that demonstration.

David Barry. And at that point there was much less controversy about the price because it also was a time when a few other drug companies were coming on with a few other drugs like ddC and ddI. And so therefore there was a great bit more optimism in the treatment of the disease.

Title reads: The White House, 1992. Demonstrators walking quietly. Eric Sawyer is among them. They carry funeral urns of various sizes and shapes. Slow drumming. They throw ashes onto the lawn of the White House. Man throwing ashes and screaming. I love you Mike!

Demonstrators hug and kiss each other, some of them are in tears. Slogan off screen. The whole world is watching! The whole world is watching!...

Horsemen try to make their way in the crowd, but get stuck in the middle of people sitting and screaming. Shame! Shame! Shame! Shame!...

Black screen.

Title reads: Peter Arno, economist, Montefiore Medical Center. There were a couple of generic drug companies, I think mainly Canadian-based generic drug companies, that wanted to manufacture AZT. They felt they could do it much cheaper and sell it at a much lower price. They in fact received FDA approval to market the generic version of AZT and as soon as that was announced, they were immediately sued by Burroughs Wellcome for infringement on their patent for the drug. [cut] But in the end the court basically sided with Burroughs Wellcome and said that Burroughs Wellcome had invented the drug and that the government did not have any rights to ownership or to the patent on the drug. This was a crucial issue because if the government had ownership rights, then it could have licensed the drug to generic companies or anyone else. (and) It could have been made available at a much lower price and made more widely available to many more people. So the ownership/patent issues, who did what in the drug world were all very important.

Title reads: Hiroaki Mitsuya, researcher, National Cancer Institute. This was done in North Carolina, in the very place of the Burroughs Wellcome company location. And the judge, the judge Howard, listened all the witnesses from Burroughs Wellcome and then he terminated the trial without hearing our testimonies. I didn't know what was happening and I didn't know that was possible to hear one side's story and doesn't hear the other side's story.

David Barry. In order to invent something, you have to have a full and complete conception what it is and what it does. What they... they had no idea what chemical Compound S was. They had no idea! And they did the testing directly at our instructions. We told them the concentration to use, we told them the assay to use, we told them in every way what to do. And the courts have said in that case, they're acting as a, quote, "pair of hands for you". They're just like your employees. They are like a lab technician. That's the way the court looks at it. And if I gave you another compound and called it "Compound Z" and said, "Put it in this tube and if the tube turns blue that means I have the cure for cancer." And you, as a technician, took it and put it in that tube and the tube turned blue, but you didn't know what the drug was, you didn't know anything else. You couldn't turn around and say, "I invented the cure for cancer!". And that's exactly the way the courts looked at it.

Hiroaki Mitsuya. It was not easy experiment to do, because I was using T cells, human T cells, normal T cells, which had to be activated with antigen and antigen presenting cells. And then he never knew what I was doing, so then that was a lie, to me²¹, because I didn't, I was not learning from them, nothing. How come? Just, AZT was brought into our lab, to my bench²², but without any instructions. What kind of instructions did I need? I don't think I got any instructions needed from any other person, because I was the only one who was propagating²³ the cells and the virus, so I don't think I got any instruction whatsoever. [cut] But the collaboration itself went well, because AZT was born, and I was very happy about it. I was very, very, very happy because I was, I thought that was my mission. One mission I thought I fulfilled. Even with later on AZT dispute over the patent and some money. I didn't care. I was so happy.

Face of David Barry. Voice of interviewer. So, did you contacted Jerome Horwitz? Do you know this man?

David Barry. I don't know Jerome Horwitz, no.

²¹To me: this precision should be translated.

²²Bench: lab table.

²³Propagating: growing.

Voice of interviewer. Did the company contact him?

David Barry. I don't know. I think he either wrote us a letter or we may have written him a letter. We know, obviously, he synthesized the drug in 1964. I don't know that he's done anything with it since then.

An old man wearing a lab coat in an elevator.

Hiroaki Mitsuya. I don't remember when we started to talk, probably 1987 or 8, and then just I was stunned at what he did in 1960's. He synthesized, he thought about, and synthesized himself AZT, ddC and d4T. Three major drugs, on himself, in 1960's.

Title reads: Jerome Horwitz, researcher, Karmanos Cancer Institute] Jerome Horwitz, the old man in the elevator, seats now in a living room. Between '60 and '64 until we published our first paper, and then '67 we published a very large paper on ddC, d4T, ddI --- a lot on these things. But in all cases, the compounds failed as far as anticancers.

New camera angle. How did AZT get to Burroughs Wellcome in the first place? Why did Burroughs Wellcome look at it? Why did Burroughs Wellcome send it to the National Cancer Institute to be tested, to Sam Broder, to Mitsuya? Well, those are all interesting questions! (and) First of all you have to understand that the Burroughs Wellcome Company, which incidentally is now part of Glaxo Wellcome Something Else, mergers take so fast these days it's impossible to keep up with everything!²⁴ But in any case, Burroughs Wellcome, at the time, when I published this paper in '64, they had in place... they had a very large antiviral program. And that's... [to his wife] I need a glass of water, Sherri... an antifungal program in place. And of course, my publication was from 1964. They made the compound, it was in their literature. Why was it in their literature? There was no use for (it for) cancer. What was the point of not publishing it. So they made the drug. And they looked at in their herpes program, in their fungal program and didn't see very much there. But they did... Hold on for one second. [Camera follows a hand passing him

²⁴The confusion of Horwitz on the new company's name after two mega-mergers should be translated. (Burroughs Wellcome became GlaxoWellcome in 1995, and is now GlaxoSmithKline, this why Horwitz got confused.)

a glass of water. He drinks.] They did see a publication by Dr. Ostertag at the Max Planck Institute for Medicine in Germany who found that AZT did stop the elongation of DNE²⁵, DNA in a mouse virus and it was on that basis that they thought, "Well, maybe just this might work against AIDS" *[cut]* Why didn't they do it in house? Well, first of all, they didn't have the requisite human materials --- the cells --- nor did they want them. They were not about to jeopardize their employees' health or risk infecting their patients --- or their employees, more accurately!²⁶ So they didn't want to do that.

Horwitz leaves the sofa, walks to the black background, and seats.

Title reads: Berlin, 1993. Man in suit speaking through microphones in the middle of crowd. If we're going to develop the drug into an oral formulation that can be used prophylactically²⁷ to prevent CMV²⁸ retinitis²⁹ or other CMV infections from ever occurring, we have to have the money to do the research. Dr. Martin Molly is in charge of that research. It's going into phase I, and we hope to have good news about that in the future. But we have to have the funds to do that as well.

A young man wearing a green shirt. The fund is a joke! You're the most profitable company in Sweden! They know they have a product that people don't have a choice. It's not a car they are selling. It's not a commodity that, if you like it, if you can afford it you buy it, if you don't you do without. People who can't get this drug die. CMV, it's more than 40% of people with AIDS. It's causing wasting. It's causing CMV retinitis. It's causing death. *[Man in suit is silent, ambarassed.]* And anyone who is not able to, ... either they failed on other drugs Acyclovir or [???] ³⁰, which is less than a third of the price, they have to take Foscavir. And those people who have to take Foscavir don't have a choice: that price have to be paid, and our system is paying for it.

²⁵Can omit this hesitation.

²⁶May omit this hesitation when writing subtitles.

²⁷An oral formulation that can be used for the prevention of CMV.

²⁸CMV: cytomegalo virus.

²⁹CMV retinisis is a condition affecting the retina and causes blindness.

³⁰Omit, not understandable in the original soundtrack.

Man in suit. David, find me one person who asked for free drug and didn't get it.

An angry young blond man. How much money does the drug cost Ken?! Getting the drug free is not the issue! It's the price you're charging us! We paid to develop it. Access is not the issue! Price IS the issue! Don't confuse the issue! It's not access! Anybody who can get this drug, that can afford \$30,000 a year --- but access is not the question! PRICE is the question! JUSTIFY THE PRICE!!! JUSTIFY THE PRICE!!! Tell us why it cost \$30,000 a year! Show us WHY it cost that much!

Man in green. We right now have in America, where companies --- private companies --- that do their own insurance are currently being able to deny an AIDS patient, give a limit of 50,000.³¹ These drug prices are one of the reasons. Well over 30,000 is a reason that, with just that drugs alone people are out of insurance. And then, when they get out of insurance, they don't have to pay out of the pocket and ask you to provide it free. When they get out of insurance, they got under medicaid³² roll. So the government --- and that means us --- is paying for it. Astra is getting its money with a facade of the fair program³³ for one patient who needs it will get it free. All of us are being bled by this exorbitant price!

A voice off screen. What do you have to say? Justify the price.

Man in suit. All I can say is that it cost a \$100 million to research this drug...

Voice off screen. Prove it!

Man in suit. Ongoing research is occurring to develop an oral formulation that will be much more effective, safe, and able to be used prophylactically. It cost money to do research.

³¹Insurance companies put a \$50,000 cap on health expenditure refunds for one person.

³²Medicaid is a kind of health coverage for the poorest in the US.

³³Fair program: program of free drug donation for the poorest people. Mostly symbolic since as the man says medicare already covers the poorest people.

*Title reads: Trevor Jones*³⁴, vice president for research, Burroughs Wellcome. After a silence. The Concord Study was really quite an interesting time in the history of AZT. Here we were with data from America which was clearly there and which all the world experts had agreed in the indications and so on. And then the experts in France and the UK said "well we want to do a study, almost identical". [cut] And so this study was set up, a study which would truly look at the early use of AZT. And this is the so-called "Concord Study", because it was like a concord³⁵... a cordiale if you will... an entente cordiale³⁶.

Mark Harrington. The British and French had the opportunity to stop their study, the Concord, and they said, "No", much to the dismay of Burroughs Wellcome. I think a lot of the American researchers looked down on the French and English and said that they were naïve and old fashion, they were holding on to old standards that actually looked at survival as opposed to new standards like laboratory markers like CD4 counts. Well anyway, in '93 the results of the Concord study came in and they were very clear. The early AZT it was an AZT vs. a placebo until you went below 200 CD4 cells and then everyone would get AZT.³⁷ So in the Concord study, the AZT group did have a CD4 cell rise but they had no difference in survival, they didn't live longer and so that showed that the benefit of AZT given too early was so small that eventually it disappeared, it washed out.

Trevor Jones. A number of patients dropped out of the study. Either because they had side effects or because perhaps they died in a motor traffic accident or whatever³⁸. And so then the amount of data that eventually came out of that was not really as robust as the amount of that one would normally like from a clinical trial.

Mark Harrington. I think people had been hoping that they'd

³⁴Jones' accent is very British.

³⁵From here Jones tries to speak French but gets confused in the way.

³⁶Entente Cordiale: an informal peace agreement between the British and the French after the Napoleonic wars, and after centuries of anglo-french fierce rivalry. May omit while keeping in mind the clumsy amusing flavor of Jones' last sentence.

³⁷May take advantage of translation to clarify. Harrington means that 1) people started the trial either on AZT either on placebo, 2) whenever a patient in the placebo group had his/her CD4 count dropping below 200, this patient would leave the placebo group and go on AZT. The important message of this sentence and the next is that people on AZT did not live longer than those on placebo.

³⁸He speaks about human lives here. "Whatever" should be translated.

be able to poke holes in the study or that there were things about it that undermined its validity, but they were unable to do so; the presentation was very clear and straight forward.

Title reads: Berlin, 1993. Activists showing a pamphlet to camera with headline reading "Early treatment benefit beyond two years".

First voice. Overnight conference report. It says that, basically, AZT is wonderful -in the face of all the data presented yesterday and in the last few months.

Other voice. Spin doctor Volberding --- does it again³⁹ --- one has to wonder how much you got paid to say that SHIT. [Volberding's face and name are printed on the pamphlet.]

Eric Sawyer. People were like "Why am I taking this horrible drug that gives me diarrhea or nausea or headaches and made me tired that I'm paying a lot of money --- thousands of dollars a year --- for if it's not doing anything to extend my life. What, am I crazy?" So immediately a lot of people, myself included, who had been taking that drug for more than two and a half years stopped.

Trevor Jones. And of course with all this publicity around --- and was AZT going to survive... Almost overnight the shares were hit quite badly. Now our job was to get our medicines out to the public. Our job was to do decent research. Our job was to manage the business. The market would reflect as it wished.

Mark Harrington. This was a time of major despair in the treatment community. The epidemic curb meant that people were, more and more people were dying every year, and more and more people were getting sick and I already told you about how Act Up was falling apart because of death and infighting.

Title reads: New York, 1994. A blond man in tears. I'll miss Aldyn McKean and Bob Rafsky. And so many of the beautiful face that have been here, and that are now gone.

³⁹Spin doctor Volberding --- does it again: can be understood as "Mad scientist Volberding strikes again".

I think to myself that there is so much work to be done. And all I feel is weary. I'm so tired, because I'm such a bad treatment activist. I wanted to be a treatment activist because I thought I could help keep my friend alive, and I'm failing... [Deep sigh.] I loved Aldyn McKean, and I know that like most you I will miss him very much.

Fix shot on a crown of flower floating in the sea. Image goes out of focus.

*Title reads: New York, 1994. Room with huge graphics painted on the wall. An extremely skinny man seats down. Another man gives him a microphone. Skinny man. I'm going to be nice for like 5 minutes, and then I'll get the discussion to real nasty. So this is "nice". Euh,... These are all the Act Up T-shirts that I've bought over the past several years. I donate them to Act Up. [He throws a plastic bag on the floor]. Does anybody like Lipisorb? It's dietary supplement. I can't use it anymore. Does anybody on the floor want it? This is probably the last I'll BE here. [He takes a picture of the audience with a disposable camera.] Euh... The gay episode of *Frazier*⁴⁰ is on tomorrow... Euh... [He looks for some paper] OK that's it. This is called "Act Up-New York's failures since the death of Robert Rafsky". Can everybody hear me?*

Voices in the audience. Yes!

Skinny man. I should be at Christopher Cause memorial service, by all the rights, but I am so god dam angry at Act Up that I am HERE tonight! I just got out of the FUCKING HOSPITAL, where I've been for the last MONTH! I am not Andrew Sullivan a near conservative British gay editor. I am not even David Lavenslought in South Carolina for a New York Times Magazine article.⁴¹ I've always been an activist, and demonstration participant. I actually went to Act Up very first demonstration downtown, at Wall Street, against the high price of AZT. I was diagnosed HIV-positive in the summer of 1987. A few week later, I found myself to the Lesbian and Gay Community Services Center. I wanted to join Act Up from the start, and go to the meetings every

⁴⁰Frazier: a popular sitcom in the US. This side remark adds to the casual style of the speaker.

⁴¹This sentence could be summarized by by appending to previous sentence "...or some journalist selling crap to the New York Times".

week. I joined completely out of self interest and self preservation. I wanted to live. I've been arrested inside St. Patrick's Cathedral, and at the FDA⁴². I've also been arrested in such non-AIDS demos such as the [??] abortion block, and other St. Patrick's Cathedral demonstrations.⁴³ I risked arrest at many more actions, most recently at the Hoffman-LaRoche demo, a year ago, January. I took my first pill of AZT at an Act Up meeting. This is probably my LAST. [cut] If Act Up continues in this fashion, it may as well be plowed in the same mass grave that is already overflowing with the rotting corpses of our friends who have died of... AIDS. And if anybody applauds they're just applauding their own STUPIDITY! Thank you. I got to go now. I have to go. I don't want to talk to anybody. I had it.⁴⁴ Thank you for your attention.

He leaves his seat. His pants fall because he has become so thin. He puts it back and leave the room. Stunned silence of the audience.

Mark Harrington. I also had developed a little bit of thrush, which is a fungal infection in the mouth and a little weight loss and just everything wasn't looking so good. And I went to the Vancouver AIDS conference which is the conference where they introduced the combination therapy approach. (and) There's some really very dramatic results both in the laboratory where the viral load goes very, very low and in the clinic where some of the early studies using the triple therapies with the protease inhibitors had greatly reduced death and AIDS in the people who had taken them. So I was really lucky: I had taken nothing at all until that time. (and then) I was able to start on combination therapy --- triple, highly-active antiretroviral therapy or HAART⁴⁵.

Eric Sawyer. Because I had taken most of the drugs in monotherapy and some of the drugs in two-drug combination therapy, I had obtained some resistance to many of the drugs and I was actually on three different triple therapies that would work for three or four months and then

⁴²FDA: Food and Drug Administration, the drug regulatory authority in the US.

⁴³May stop translation of the sentence after "non-AIDS demo" (voice of speaker is fast and he refers to events only known by Act Up-New York activists).

⁴⁴I had it: I'm fed up.

⁴⁵HAART: Highly Active Anti-Retroviral Therapy, acronym popular in the scientific literature. May omit.

start to fail with initial decreases in viral load and increases in T4 counts and then have it collapse and start going right back to high viral load -low T cell count. So David Ho's lab and my doctor did phenotyping, genotyping, drug sensitivity tests, a whole kind of very expensive detailed laboratory test to find out what drugs I had some benefit from and they designed a five-drug cocktail that they put me on which is extremely toxic [cut] I have a lot of side effects. I take 6-7 drugs to counteract the side effects of that cocktail. I have to take Ritalin because I'm so exhausted from the impact that those drugs have on my body. I have to sleep 8-10 hour a day or I can barely walk. My hip joints are deteriorating from the toxicity of the drugs --- I may have to have a hip replacement... They're no picnic⁴⁶, these drugs... But I'm still alive, probably more than 20 years after infection.

Title reads: Vancouver AIDS Conference, 1996. Man under sunlights. I am pleased to introduce one of the founders of Act Up-New York, Mister Eric Sawyer.

Eric Sawyer on podium. He wears a suit. Distinguished guests, I am going to be very blunt. I'm here to sound a wake up call to everyone attending this conference. I am afraid that you all will miss the real message from this conference. I speak especially to the media, who have started the spin that the "the cure"⁴⁷ is here, let's dance." If you think the cure is here, think again. The cure is NOT here.

The fact that the protease combination drug treatments are showing a lot of promise in the blood tests of the very few people who can get them, does not mean that the cure is here. Yes, the preliminary results from these hugely expensive combination treatments look great. But we are a long way from a cure, even for the rich who can afford the treatments. And we are no closer to a cure for the majority of people living with AIDS on this planet than we were ten years ago. Most people living with AIDS can't get aspirins.

⁴⁶No picnic: no fun.

⁴⁷Translators should be very careful to distinguish between "cure" and "treatment". A cure eliminates a diseases forever in a patient, a treatment does not necessarily do so. This distinction is essential in order to avoid confusing viewers, especially AIDS patients currently on treatment. Sawyer says that while there is no *cure*, there are effective *treatments* that must be made available to all.

We must end the greed, because greed equals death. We must end the greed and demand access for all.

Raising his fist and screaming louder and louder.

Greed kills - Access for all!

Greed kills - Access for all!

Greed kills - Access for all!...

Image and sound are bluntly turned off and replaced by a black screen and a low volume camcoder buzz.

Rolling trailer.